

Epidemiology of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation

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Abstract

A two year prospective study was performed to determine the epidemiology of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation in the UK and the Republic of Ireland. Cases were notified to the British Paediatric Association Surveillance Unit from September 1992 to August 1994 if a formal case conference had been held for the first time during that period to discuss any of the above conditions. A total of 128 cases were identified: 55 suffered Munchausen syndrome by proxy alone, 15 poisoning, and 15 suffocation; 43 suffered more than one type of abuse. The majority of children were aged under 5 years, the median age being 20 months. On 85% of occasions the perpetrator was the child's mother. In 42% of families with more than one child, a sibling had previously suffered some form of abuse. Eighty five per cent of notifying paediatricians considered the probability of their diagnosis as virtually certain before a case conference was convened. The commonest drugs used to poison were anticonvulsants; opiates were the second commonest. Sixty eight children suffered severe illness of whom eight died. The combined annual incidence of these conditions in children aged under 16 years is at least 0.5/100 000, and for children aged under 1, at least 2.8/100 000.

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Derived from Asher's description of Munchausen's syndrome¹ the term Munchausen syndrome by proxy was first used to describe fabricated illness in childhood in 1977.² Since 1977 this form of child abuse has attracted considerable media attention and controversy. There has been debate concerning the most appropriate name for this type of child abuse. Alternative names include factitious illness by proxy, fabricated disorder by proxy, and Meadow's syndrome. An agreed definition of what constitutes abuse by Munchausen syndrome by proxy has also been the subject of recent discussion.³⁻⁵ Although imperfect, a practical definition of Munchausen syndrome by proxy child abuse is: when an infant or a child is presented to doctors, often repeatedly, with a dis-

ability or illness fabricated by an adult, for the benefit of that adult.

Non-accidental poisoning of children was reported by Rogers *et al* in 1976⁶ and the literature has been reviewed in detail by Dine and McGovern.⁷ Non-accidental suffocation of children has been recognised more recently.⁸⁻¹² The diagnosis of deliberate suffocation has been facilitated by the use of polygraphic recording and has been observed using covert video surveillance.¹⁰⁻¹²

The purpose of this study was to determine the epidemiology of these three conditions. It is clinically apparent that these three forms of abuse are related and overlap. For this reason, as well as because of their relative rarity, the conditions were studied collectively.

Methods

New cases of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation in children aged under 16 years, diagnosed or suspected in the two years from 1 September 1992 to 31 August 1994 (inclusive), were reported by consultant paediatricians in the UK and the Republic of Ireland, to the British Paediatric Association Surveillance Unit (BPASU). The BPASU provides an active reporting system for the surveillance of certain serious childhood diseases.¹³ A report card containing a list of conditions is sent monthly to all consultant paediatrician members of the British Paediatric Association throughout the UK and the Republic of Ireland (this includes virtually all consultant paediatricians in these two countries), as well as to other categories of members where appropriate. Consultants are asked to report cases of conditions named on the card that they have seen in the preceding month, or to tick a 'nil return' box. The conditions of Munchausen syndrome by proxy, non-accidental poisoning, and suffocation were included on the card for two years during the period above. The criteria for notification were any infant or child aged under 16 years for whom a child protection conference had been convened because of suspicion of one or more of the following: (a) Munchausen syndrome by proxy, defined as: 'an infant or child presented to doctors with a disability or illness fabricated by an adult', (b) non-accidental poisoning, defined as: 'an infant or child who had been deliberately poisoned (using any agent, by any route) by an adult', or (c) non-accidental suffocation, defined as: 'an infant or child who had been deliberately suffocated or asphyxiated by an adult'.

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When a case was reported to the BPASU, the information was sent to one of two study administrators located in Leeds (RJM) or Cardiff (PMD), dependent on the geographical location of the notifying paediatrician. Each reporting paediatrician was then requested, by post, to complete and return a detailed four sided questionnaire regarding the details of their case. No contact was made, either directly or indirectly, with the index child or his/her family.

Paediatricians were also requested to supply a detailed case summary that had been rendered anonymous. These case histories were examined in depth by the study authors jointly. This examination was to determine whether cases, in which poisoning or suffocation was reported alone, appeared to be happening in the context of Munchausen syndrome by proxy, that is, the child was repeatedly presented to doctors with a fabricated illness perpetrated by an adult. Those that satisfied this criterion were then recorded as a case of Munchausen syndrome by proxy in addition to the abuse reported by the notifying paediatrician.

Data were analysed using the Access Database Package (Microsoft Corporation) and the

Statgraphics statistical package (Statistical Graphics Corporation). The comparison of Poisson rates procedure was used to examine gender and regional differences in incidence. The Kolmogorov-Smirnov one sample test was used to examine seasonal trend.¹⁴

Results

The total number of confirmed cases in the UK and the Republic of Ireland, during the two year period 1 September 1992 to 31 August 1994, of children incurring Munchausen syndrome by proxy, non-accidental poisoning, or non-accidental suffocation was 128. Two hundred and ten notifications were received but 82 were excluded from the study because of: duplication (52), non-satisfaction of notifying criteria (26), and inability to obtain a questionnaire (4).

Cases did not satisfy the inclusion criteria either because the original case conference was held before the study period, no case conference was ever convened, poisoning was self inflicted, or there was an administrative error.

ANNUAL INCIDENCE

The total number of children aged under 16 years in the UK and the Republic of Ireland in mid-1992, based on the last population census performed in each country (1991 census; Office of Population Censuses and Surveys, and Central Statistics Office for the Republic of Ireland), was 12 725 936. As 128 cases were identified over two years this means that for the two countries combined the annual incidence of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation was 0.5/100 000 children aged under 16 years. In a hypothetical district of one million inhabitants therefore, the expected incidence would be approximately one child per year.

The majority of cases (77%) were aged below 5 years (fig 1). The annual incidence for this age group during the study period was 1.2/10 000 children (based on the 1991 census). The peak annual incidence occurred in the first year of life (2.8/100 000 children aged under 1 year).

REGIONAL INCIDENCES

The rates in the health service regions, as they were before 1995, showed large differences (fig 2). The highest regional rate was in the Yorkshire region (0.8/100 000 children aged under 16 years/year). This was seven times that of the lowest regional rate as shared by the Republic of Ireland and North East Thames (0.1/100 000 children aged under 16 years/year) ($p < 0.01$).

INTER-RELATIONSHIP OF ABUSE

Figure 3 shows the number of cases of each abuse type that were perpetrated alone and in combination. Munchausen syndrome by proxy occurred in isolation on 55 occasions. Fifteen cases of poisoning and 15 of suffocation occurred in isolation and were not associated with a history of repeated presentation of fabricated illness to doctors as an attention seeking

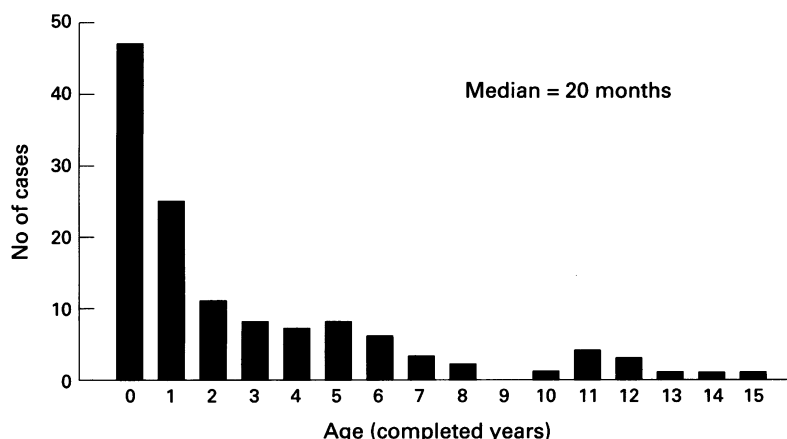


Figure 1 Distribution of age at time of diagnosis.

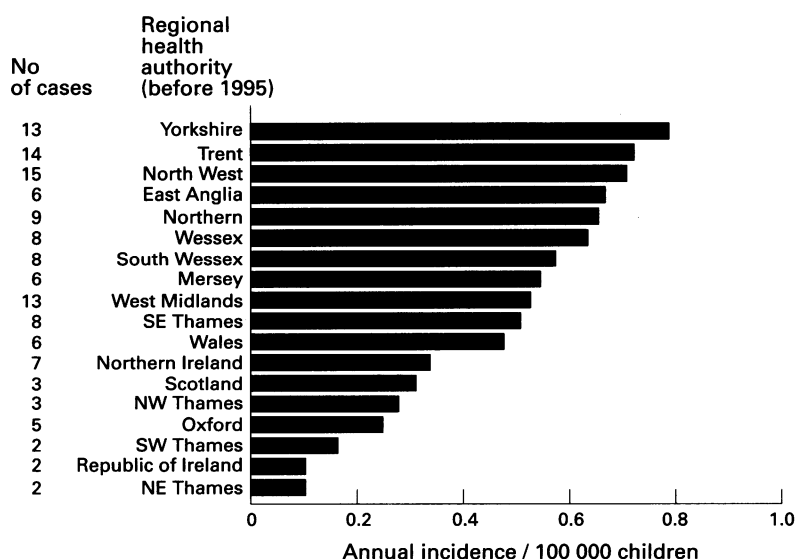


Figure 2 Variation in annual incidence between different health authorities (as they existed before 1995).

behaviour by the perpetrator. The remaining 43 cases involved two or more of the forms of abuse being studied.

GENDER

There were 60 boys (47%) and 68 girls (53%). The difference was not significant.

SEASONAL VARIATION

There was no significant deviation from a uni-formed seasonal incidence pattern.

AGE AT DIAGNOSIS

The median age at diagnosis was 20 months. The distribution of the child's age at diagnosis was very heavily skewed towards the younger age groups (fig 1).

MODE OF PRESENTATION

Ninety two cases (72%) first presented to the notifying paediatrician as an acute medical 'problem'. This included emergency '999 calls', presentation at an accident and emergency department or as an acute hospital admission, authorised by a general practitioner. Non-acute medical presentation, usually as an outpatient referral, was the next commonest with 31 cases (24%). The five remaining children first presented as part of a child protection procedure. In eight cases abuse was observed during covert video surveillance.

PRESENTATION OF SCHOOL AGE CHILDREN

Thirty children were aged 5 years or over when diagnosed of whom 19 suffered from Munchausen syndrome by proxy alone. Five children had been identified as having severe learning difficulties before their abuse. Known causative conditions for their developmental delay were Down's syndrome (2) and ornithine carbamoyl transferase enzyme deficiency (1). The aetiology was unknown for two children; one suffered sensorineural deafness and profound hypotonia, the other had severe epilepsy. The other children abused by Munchausen syndrome by proxy were intellectually normal and therefore must at least have passively colluded in their abuse. Eleven were poisoned, of whom nine also suffered from Munchausen

Table 1 Range and frequency of use of poisoning agents

Poison	No of cases
Anticonvulsants	14
Opiates	8
Benzodiazepines	5
Tricyclic antidepressants	5
Paracetamol	5
Salt	3
Antihistamines	3
Carbon monoxide	2
Household bleach	2
Others	18

syndrome by proxy. Included in these 11 were the five who had severe learning difficulties. The other six children were unaware that they were being poisoned. No cases were reported of suffocation in children of school age.

PRESENTATION OF MUNCHAUSEN SYNDROME BY PROXY

The perpetrating adult gave a false story of illness alone, without fabricating signs or test results, in 23 of the 97 cases of Munchausen syndrome by proxy. In 21 cases the adult, in addition to giving a false history, also fabricated signs or interfered with test results. Examples of this were heating a thermometer to feign fever or adding blood to urine to imitate haematuria. In 53 cases the perpetrating adult inflicted actual physical harm on the child, as well as giving a false story or fabricating signs, to mislead health care professionals. An example of this was deliberate suffocation to induce convulsions.

CHILD PROTECTION REGISTER

Sixteen (13%) children were already on the child protection register at the time of diagnosis.

CERTAINTY OF DIAGNOSIS

The notifying paediatrician was asked to state how certain he or she felt that the abuse had been perpetrated. One hundred and nine (85%) of paediatricians estimated the probability of their diagnosis being correct as greater than 90%. In 14 cases the probability of abuse was estimated to be between 71% and 90% and in four, between 50% and 70%. In only one case was the probability less than 50%. In all eight cases where covert video surveillance was used the probability of abuse was rated as greater than 90%. The probability was also rated as greater than 90% for 13 of the children already on a child protection register.

POISONS

Forty four children were poisoned; 38 different poisons were used. Seven children received more than one poison; 71% of poisons were prescribed drugs. The commonest group of poisons used was anticonvulsants, opiates were the second commonest (table 1). Carbamazepine, which was used to poison six children, was the single agent used most frequently.

PERPETRATOR IDENTITY

The mother was identified as the sole perpetrator in 109 cases (85%). The father was implicated alone on six occasions. In two cases,

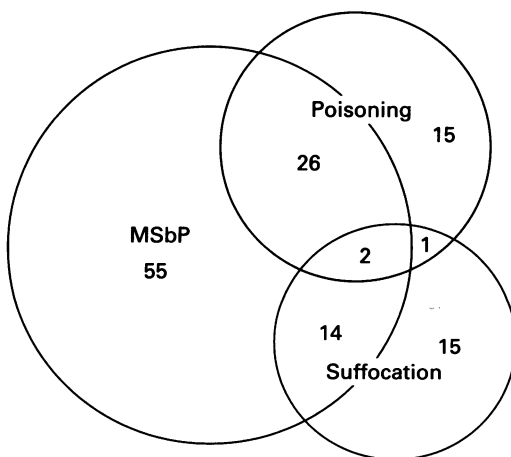


Figure 3 Venn diagram describing the numbers of children suffering each type of abuse in isolation and in combination (MSbP=Munchausen syndrome by proxy).

another adult, one a grandfather, the other a boyfriend, was implicated. In 11 cases the perpetrator remained uncertain. In only eight cases was the mother not suspected to have been involved directly. In the 97 cases that involved Munchausen syndrome by proxy the mother was identified as the sole perpetrator in 94 and was suspected in two.

SIBLING ABUSE

Altogether 83 out of the 128 index children had had at least one sibling. Fifteen of these had a sibling who had died previously (18 deaths); five of these deaths had been categorised sudden infant death syndrome.

Of the 83 families with another sibling, 34 families were known to have had a sibling who had suffered previous abuse. The incidence of each type of abuse known to have been perpetrated was as follows: Munchausen syndrome by proxy (17), suffocation (5), poisoning (5), physical (5), and abuse by neglect (5). In seven of these 34 families a sibling had died (eight deaths). In two families the dead sibling was known to have been also abused; one was suffocated, the other suffered physical abuse. Two of the deaths had been categorised as sudden infant death syndrome; two were believed not to have suffered abuse. It is unknown whether the other two children were abused or not.

SEVERITY OF PHYSICAL ILLNESS

Eight children are known to have died as a direct result of their abuse, all from either poisoning or suffocation. Fifteen more children required intensive care. Reporting paediatricians judged that another 45 children suffered major physical illness, and 31 minor illnesses. Respondents were not asked to assess the psychological harm caused by the abuse.

HOSPITALISATION AND MEDICAL INTERVENTION

By the time of diagnosis, 122 children had been admitted into hospital as a result of their abuse; 53 were in hospital between seven and 30 nights. Thirty three were inpatients for more than 30 nights.

Inappropriate invasive investigations or treatments, including drug treatment, were inflicted on 119 (93%) children. One child incurred non-invasive investigation alone. Eight children incurred neither medical investigation nor treatment.

Discussion

It is apparent that even when the incidence of these three forms of abuse is combined, they are rare conditions. To give perspective, conditions that occur with approximately equal incidence are death from drowning in children under 16 years¹⁵ and cystinosis in the under 5 year age group.

In common with many epidemiological studies, the calculation of incidence is likely to be an under estimation. Anxiety regarding legal aspects or maintenance of confidentiality may have deterred some paediatricians from notifying cases. Diagnosis of a rare condition without a suitable confirmatory medical 'test' is sometimes difficult and may have made some lack

the confidence to notify. In addition, cases may not have been reported because of: non-involvement of a paediatrician, the relevant specialist not being a member of the British Paediatric Association, or the lack of a child protection case conference either because the child was no longer at risk or had died. The large regional differences may to some degree be due to under reporting. Against these factors it is worth noting that a high percentage of report cards is returned every month to the BPASU (94.4% in 1994),¹⁶ and that over 50 notifications were duplicated.

The number of children in this study represents the largest series we know of reported cases suffering from these forms of abuse. Our findings confirm and add to the known typical features of these forms of abuse that have been reported in previous reviews.^{7 17 18} The perpetrator is usually the mother. Other siblings may have been abused previously. The child is usually of preschool age and presents most commonly as an acute medical problem. Disability is more prevalent in abused children than in the population. Prolonged hospitalisation and investigation are likely to occur before diagnosis. Anticonvulsants, then opiates, are the commonest poisons used. Suffocation is unlikely to occur in children over the age of 5 years. The median age of 20 months at diagnosis for the conditions combined is younger than previously reported.^{7 17 18} A possible explanation may be increased awareness by doctors of these forms of abuse, leading to earlier diagnosis.

The close relationship of these three forms of abuse is confirmed. While Munchausen syndrome by proxy often occurs in isolation, it appears to be very unusual for non-accidental poisoning or suffocation to occur alone. Recognition of this has important management implications.

The very high degree of certainty that paediatricians had in their diagnosis of abuse is unexpected and significant. A common claim made in the media, as well as in courts of law, is that many paediatricians may be over zealous in diagnosing these conditions. These conditions have also been called 'dustbin diagnoses', which describes the supposed practice of paediatricians labelling cases, that they are unable to diagnose otherwise, as abuse. Our findings suggest that most paediatricians do not make this diagnosis on tenuous evidence but do so only when they feel there is a very high probability of abuse.

Our findings also suggest that paediatricians feel the diagnosis has to be virtually certain before a child protection case conference is convened. It is probable that in the UK this is a consequence of several factors including the recent legislative changes in the Children Act, 1989. This resulted in parents or guardians being encouraged to be present at conferences.¹⁹ It is possible that informal meetings are now performing some of the function of conferences of the past.

Children suffered a wide range of severity of abuse. This ranged from illness fabricated by false story alone, to death. The finding that the

majority of perpetrators of Munchausen syndrome by proxy inflict direct physical harm on their children to mislead doctors is new. While this finding may reflect that a case conference is more likely when physical harm has been inflicted, it does refute any remaining perception there may be that Munchausen syndrome by proxy is a relatively benign form of abuse. In addition children suffer from unnecessary medical intervention and psychological damage.

There are several possible reasons why regional rates differed by as much as sevenfold. Firstly, true regional differences may exist. Secondly, the presence of individuals with a particular interest in these conditions will heighten awareness in some regions. Thirdly, diagnosis rates may be lower in regions where inappropriate 'doctor shopping' is harder to detect due to a high concentration of paediatricians. This would apply to regions that incorporate London. Finally, it must be stated that paediatricians in some regions may be less willing to report cases. Due to the high certainty of paediatricians in their diagnosis, it is more likely that doctors in regions with low reported incidences failed to either recognise or notify cases, rather than that those in other regions were over diagnosing abuse.

Outcome is a fundamental aspect of the epidemiology of a condition. Due to the length of time that child protection and legal processes take, a description of outcome has been omitted from this initial paper. We are performing a follow up study on the cohort of children identified in this study. We intend to report the findings in due course.

In summary, the epidemiology of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation have been described. The main findings were that the conditions are rare, with a combined annual incidence of 0.5/100 000 in children aged under 16 years, the perpetrator is almost always the mother, in contrast to other forms of abuse, and the median age of the child at diagnosis is 20 months. Commonly, children suffer

direct physical harm as part of the illness fabrication. This can lead to severe illness or death. Anticonvulsants are the most frequently used poisons. The three forms of abuse commonly overlap and their close relationship is confirmed.

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